Witness Name: Barbara Marsella
Statement No: WITN2772001
Exhibits: WITN2772002-WITN2772004
Dated: October 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BARBARA MARSELLA

I, Barbara Marsella, will say as follows:-

Section 1. Introduction

1. My name is Barbara Marsella. I live at GRO-C Dorset GRO-C GRO-C. My date of birth is GRO-C 1953. I live with my husband of 40 years, Richard Marsella, who is providing his own statement to the Inquiry under Statement No. **WITN2773001.** We have two children, Mark and Penny, who were born in 1984 and 1986 respectively.

2. As a result of receiving contaminated blood products, I was infected with Hepatitis C. I have since been cleared of Hepatitis C; however I now suffer from end stage liver disease.

3. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

4. Richard and I met on a blind date in the 1970s. He was working as a delivery driver for a greengrocers and I popped into the store, which was run by my friend's

husband. My friend rang me and asked if I had noticed the delivery driver, but I hadn't. Richard however had noticed me and following a successful first date, we married five years later.

5. In 1983, I fell pregnant, but soon after the doctor signed me off work and I wasn't able to return to work until a long while after. I later suffered a miscarriage.

6. On GRO-C 1984, following the birth of my son Mark, I received a blood transfusion at Kingston Hospital. I suffered excessive blood loss and believe this blood was infected with Hepatitis C. I was under the care of Dr May during my stay. A page from our baby book has been exhibited as per **WITN2773002,** which confirms these details.

7. Prior to this, I had no health issues whatsoever and had not received a blood transfusion before 1984.

8. I believe my pregnancy was quite normal and other than indigestion, I had no issues. Prior to labour, I had already decided to remain in hospital for a week after giving birth. Mark was born normal and two days after I delivered, I woke in the morning and my joints felt very stiff. I cannot recall the exact circumstances at the time, but I remember the doctor arriving and informing me that my symptoms indicated a lack of blood. I was blood group rhesus negative and anaemic, so the doctor decided to give me a blood transfusion.

9. Richard was not with me at the time and by the time he arrived, I had already had the transfusion. It all happened very quickly and all I recall were these plastic bottles, containing the blood products. I took no notice of it as there was no reason to suggest we should be doubtful at that time.

10. I was kept under observation for ten days, to ensure that I had enough blood. During this time I had blood tests almost every other day. It was almost as though someone knew of the risks involved. My current liver nurse said the day I had the transfusion is the day I got Hepatitis C. Given all those blood tests, why did they fail to identify the Hepatitis C sooner?

11. My mother stayed with me for a week after I returned home. By the time Mark was four weeks old, I was back to normal with no issues. Thereafter, I never received any correspondence or follow up requests from the hospital, aside from a post natal appointment and normal visits from the midwife. Anytime I visited my GP, nothing significant was said.

12. When I gave birth to Penny two years later, there were no complications involved. It was a slightly longer labour, but I never received any blood products and was home within three days.

13. I was not provided with any information about the risk of being exposed to infection from blood products. In those days, hospitals never discussed things like that. If there had been any sign or thought of risk, we would not have consented to the transfusion. Unfortunately, like everybody else, we didn't question doctors about their recommendations.

14. In the past, there was a scandal with the proposed morning sickness tablet, Thalidomide, which caused stillbirths. My Nan was subjected to this and she was never herself again. By the time she realised the risks involved, the drug was taken off the market. Similarly, importing blood products from the USA which originated from prisoners and drug addicts was very experimental. We didn't have a clue about any risks.

15. For a very long time, I felt well and never any different in my mind, until my friends, whom I had known for over 40 years, pointed out that I was not as lively as I used to be. It was nothing major but little things started building up.

16. Six months prior to becoming very ill, I became sallow and my eyes had turned yellow. The virus lay dormant within me for years but unbeknownst to me, had been eating away at my liver. Suddenly and spontaneously, my health declined rapidly. In 2006, I was diagnosed with borderline diabetes. I attended a clinic where I learnt what I should and should not eat. I was not taking medication for diabetes and it was always diet controlled. My condition was monitored through annual blood tests and the results revealed that there was no cause for concern.

17. I was informed that I had Hepatitis C in April 2017. In January 2016, I had pains in my arm and consulted Dr McKinstry at the Village Medical Practice, who referred me for blood tests. The results returned abnormal so I was referred to a doctor at Poole Hospital. She conducted blood tests and said she would refer me to Dr Nicholas Sharer.

18. Unfortunately Dr Sharer's clinic was very full and it was extremely difficult to be seen by him. Appointments were made but cancelled on a number of occasions. It took a while to see him and when I did, in January 2017, he mentioned a letter he had been sent stating that they had identified scarring on my liver dated before Christmas 2016. He questioned me on my alcohol intake and I replied that I had the occasional drink, but I had never drunk excessively. If Richard opened a bottle of wine, we would finish it but that was not a regular occurrence. At this consultation, Dr Sharer also asked me if I had ever received a blood transfusion, to which I mentioned the incident in 1984.

19. Dr Sharer said he would arrange for me to have an endoscopy but this was also cancelled several times. At this point, I was still not diagnosed with the Hepatitis C virus. In March 2017, I was going away on a short cruise. On Dr Sharer's advice I chose not to drink at all and since January 2017, I have not had a single drink.

20. In April 2017, and upon my return to the UK, I was rushed into hospital. I had woken up in the morning on Easter Saturday, completely unaware of my surroundings and unable to get out of bed, because my legs and stomach had swollen up like a balloon. Richard said I was unrecognisable. The paramedics couldn't figure out what was going on with me nor would they believe that I was not ordinarily that size. I was taken to Poole Hospital and remained as an inpatient until Easter Monday. During my admittance, I was again questioned on my alcohol consumption. They asked me when I last drank and I said I had not drunk since the end of January. The doctor simply could not understand it.

21. Two days later, Dr Sharer came to speak with me at my bedside. From our discussion in January 2017, he put two and two together and asked whether I

remembered when he questioned me regarding blood transfusions earlier that year. He then went on to break the news of my Hepatitis C infection.

22. Richard told me not to answer any questions I was unsure of and to be honest with Dr Sharer. Although at that consultation Dr Sharer was talking to me, I cannot recall anything other than him telling me I had Hepatitis C. I wish they had spoken to Richard instead but they felt obliged to tell me first.

23. Upon diagnosis, I was told I was experiencing liver failure and that they would try to do anything they could to help. I was informed that treatment was available and would ensure I got it. I was not completely capacitated as I was being pumped with fluids in my legs, knees and stomach.

24. I was eventually discharged on 3 May 2017. Dr Sharer discussed the treatment plan thereafter. Dr Sharer also mentioned that Richard and my children should be checked for Hepatitis C. They all thankfully later tested clear.

Section 3. Other Infections

25. We are not doctors, so we do not know if I received any other infections, other than Hepatitis C as a result of being given infected blood products.

Section 4. Consent

26. As far as I was concerned, I woke up in the hospital that day, had a problem and the solution was to get a blood transfusion. If I had known that there was a risk involved with that, I would have refused; therefore I did not provide informed consent.

Section 5. Impact of the Infection

27. I am trying my best to cope with my Hepatitis C infection and liver disease, but I still have my off days and sometimes do not get out of bed, as I feel I have nothing to get up for. This is not the attitude to have and is certainly not the person I once was. I used to leave the house at 7am every morning in order to take the children to school, go shopping and meet with friends and family. I also worked for Bistro Vino

alongside Richard. Eventually we were offered the opportunity to run our own restaurant (one of six in the franchise). When I think of what I used to put into a day and how much I can do now, it's significantly different. I have no energy to do anything.

28. When I was well, I was always up and about and handled all the cooking and cleaning. For hours I would not leave the kitchen, but now I get very confused. Even whilst cooking a meal, I forget whether I've added certain ingredients into my recipe. This impacts the taste of the food; sometimes I add too much salt or sugar or if I am making eggs on toast, I will cook the eggs and forget the toast. As a result, Richard does all cooking now.

29. I can manage handling small chores such as loading and unloading the dishwasher, ironing and washing, but anything I do, I cannot do for long. In comparison, I can spend hours in the day sitting and watching TV. Again, Richard has taken over much of the household maintenance.

30. As a result of having Hepatitis C, I was diagnosed with type 2 diabetes and end stage liver disease. My health will probably not improve and the only method of treating my liver is to look after myself and monitor it. A small chunk of my liver is still functioning and I have to ensure that nothing happens to what is left. For this reason, I ensure that I go to the loo at least twice a day and that I eat and drink well.

31. Since falling ill due to liver damage, my diabetes has become worse. My potassium levels need to be kept under control. I didn't need tablets before as it was all diet controlled, but now I need metformin. My dosage increased from 500mg to 1000mg.

32. I have been receiving ongoing treatment for my conditions and take several tablets a day. My consultant, Dr Sharer, started clearance treatment in 2017, which consisted of Harvoni and Ribavirin for a 6 to 12 week period. We couldn't believe it was that short as we had heard of the usual Interferon treatment lasting between 6 to 12 months. I was told that Harvoni doesn't work for everyone.

33. Since the treatment was very expensive, costing approximately £200,000 per course and £2,000 per tablet, the doctor had to get authorisation from the board. We did not

have time to wait for the next board meeting as I was in the end stages of liver disease, so he went ahead anyway.

34. Richard said the cost did not matter and said that if needs be, we would be willing to pay for it ourselves.

35. It almost felt as though they were examining whether I was worthy of this treatment. It was subtle, but they must have wondered if I was a drug addict or an alcoholic, which is absurd. I couldn't even become a drug addict, because even during blood tests, trained nurses have struggled to find my veins.

36. I didn't understand how ill I actually was. I suffered from terrible itching and still get rashes today. I also felt extremely lethargic and could fall asleep in the blink of an eye. Furthermore, I lost my appetite due to feeling nauseous. I was unable to manage the sickness as the feeling was spontaneous and came very quickly with very little lead up. Richard forced me to eat food.

37. Despite the side effects named above, I remained on the course for 12 weeks and was able to finish it.

38. The course of treatment was successful and I was cleared of the virus I was overjoyed that my course of treatment was fairly short however I was still ill for another year and it has taken a long time to get where I am now.

39. I went for regular blood tests every two months to ensure the virus had not returned. I was informed that if Hepatitis C had not returned within six months of it being cleared, I would not relapse at all. Nevertheless I was tested for up to a year and that prognosis appears to be correct.

40. In January 2018, I started feeling extremely unwell and sick. My GP phoned the hospital and explained that he was sending me there right away and requested that they ready a bed for me. I was admitted for a week. To my knowledge, the infection had cleared. They said there were no signs of the Hepatitis C virus. I was last tested in April 2019 and am not due another test now until October 2019.

41. I have not had a sip of alcohol since 2017 and do not even fancy it anymore. In order to stay as healthy as possible, I have to maintain a good diet. As a result, I have to check everything on packaging and feel as though my life has become all about labels. I cannot eat food high in salt, sugar or carbohydrates. A nutritionist has advised to eat breakfast foods that do not turn to sugar or carbs and we have discovered that foods considered healthy are not so, such as porridge oats. The biggest issue is salt and this prevents us from going out for meals. Sometimes we take a chance as we want to live, but we have to be extremely careful that nothing is eaten in excess. It has been a constant battle finding things to eat and deciding what to eat for every meal of the day.

42. My liver condition has completed changed my life and how we are living now, is entirely different to how Richard and I imagined our retirement to be. We were supposed to live a happy life without any stress or care in the world. Instead we cannot even enjoy the simple things. If I wanted a cup of tea, I would have to stop myself as I have already had one in the morning.

43. On top of this, I have lost some of my independence as Richard now has to be around me all the time. We used to do our own thing. If I wanted to go out by myself I would and he would also get a break from me, but that is just not possible anymore.

44. Richard and I used to have a very big social life, particularly when our children were younger. We would host dinner parties and social gathering with friends and family. Nowadays, even a day trip is difficult. I get very tired and cannot walk very far at all. It is awkward having to tell people why I am unable to do these things anymore and I feel like I constantly have to make excuses. Even when I meet other people, my health is all we can talk about with others. As a result, we don't make very many plans.

45. If there is a wedding, we have to tell people that we would love to come, but it all depends on my health that day. For this reason, I cannot make arrangements to go on holidays with friends or family. In the past I have had to cancel one of my holidays. If we plan an excursion or day trip, I may be unable to commit due to my

health. Will I be able to get up in the morning and if I manage that, will I get tired later on?

46. Now we hardly have much of a social life and all we really do is go to the theatre in the West End. Even then, as it requires a day trip, we have to worry about food and finding a healthy place to eat. In addition to this, going to the theatre requires us to travel into London and I find getting on public transport exhausting. I also feel overwhelmed by the crowds and the noise.

47. I am a massive fan of watching Tennis and so Richard and I went to Wimbledon this year. However after the match was finished, all I wanted to do was go home, whereas before, I would have stayed out for much longer.

48. I have been very forthcoming about my infections and have suffered very little stigma from friends and family. I felt more stigmatised by the staff at the hospital as whenever I go to the Hepatology department, the nurses ask me about my alcohol consumption. It is just a preconceived notion. I do not feel I deserve this treatment as other people have needed a liver transplant and start drinking as soon as they have a new liver. On the other hand, I have not had a drink since early 2017 and I do not plan on ever drinking again.

49. Luckily, I have had no issues with my dentist. My hygienist said that my teeth were doing strange things because of the Hepatitis C, but never fussed over them.

50. Financially, we have struggled to cope. After the birth of my children, I had numerous part time jobs. I spent seven years working for a cleaning company. I then worked for school meal services and eventually joined Hampshire Council as a cook. I went on to run a school kitchen and the timings matched my children's schooling hours, so it was convenient for me. I wasn't working when I became ill. Prior to this, I was also looking after my mother in law as she was unwell.

51. We are better now, but have had to sell our house and downsize to pay our mortgage off. Recently we have decided to move back to where we were, which will cost us extra money and stress. I worry about the move and having to pack things into boxes. With my memory it is not easy to recall what needs to be done and what

has already happened. Our current home is in a cheaper area but we get noise pollution from airplanes overhead. As we are older now, we want to be in a quieter area and don't want to live on a busy main road.

52. Whenever we discuss the topic of my health, Richard tends to get very upset. The impact on him has been very big as he has been the one who has had to deal with my health issues. He is also much angrier than me about what happened.

Section 6. Treatment/care/support

53. No counselling or psychological support was ever made available to me, as a result of being infected. We never asked for it. We are strong people and dealt with our issues on our own. We hardly discussed the issue and took it, as it came. It has been nice talking to solicitors about the impact of the infection on Richard and I.

Section 7. Financial Assistance

54. Dr Sharer at Poole Hospital informed me and my husband that we could get compensation from the Skipton Fund as I was infected with Hepatitis C. On this basis, we submitted an application but it was refused for lack of proof of infection.

55. The reason we had no proof was because of Kingston Hospital's policy on storing medical records. They only retained records for 8 years, as per the letter exhibited; **WITN2772003.** We also asked our GP for my records covering the year 1984; however we were informed that they had been lost. Their excuse was they had probably gone missing when my old GP had retired and things went electronic and documentation stemming back to a particular date were not archived or electronically stored. They didn't have that particular year or the year before, but they had documentation from 1985.

56. We appealed the Skipton Fund decision and before getting an answer, we were told that they no longer deal with claims and were taken over by the NHS Business Services Authority.

57. Despite the fact that we had no records to prove I had a blood transfusion, Richard and I kept a baby record in which we pasted the baby tag and cot tag. It is extremely sentimental to us. However, there was evidence of a blood transfusion written there and I also have written statements from friends and family who came to visit me, who remember me receiving the blood transfusion. A letter from Dr Sharer, has also been exhibited as per **WITN2772004**, advising the only source of the infection would have been the transfusion.

58. We were at our wits end when my consultant advised us to contact our local MP, GRO-C, for help. GRO-C wrote a letter to Jeremy Hunt. We have since reapplied for compensation through the NHS Business Services Authority and the panel reconsidered my appeal on 16 April 2018.

59. We got through eventually with them and they accepted the fact that I received the transfusion. I received the Stage 1 payment of £20,000. As this was backdated, I received an extra £3,696.70. I also receive £333.33 monthly.

60. I now have cirrhosis of the liver, so receive further monthly payments of £1,262.50.

61. Overall, it has been a long winded application. It was mainly the Skipton Fund with whom we had issues.

Section 8. Other Issues

62. I felt that there were a lot of firms who did not want to take on our case as we were not a case regarding a haemophiliac who received regular blood products.

63. I believe that someone in the department knew that the blood I was given was contaminated. Moreover, somebody authorised that blood to come into that hospital and into the country and that person would have known of the risks, especially considering in the USA, contaminated blood was all over the media.

64. On YouTube, Richard and I have seen prisoners and drug addicts queuing up to donate blood in exchange for payment. These are high risk individuals!

65. The main thing we want to know is why it all happened and who is responsible. I still believe no one will own up to what happened in the past, but I want those people to know how much their decisions have changed our lives and I would like answers.

Anonymity

66. I would not like to be anonymous and understand that this statement will be published as part of the Inquiry.

67. I do not want to give oral evidence.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed........GRO-C..........

Dated..........17/10/19...........